



European Monitoring Centre
for Drugs and Drug Addiction

User-led interventions: an expanding resource?

Background paper commissioned by the EMCDDA for
Health and social responses to drug problems: a European guide

Author

R. Webster

2017

User-led interventions: an expanding resource?

Russell Webster

October 2017

This paper was commissioned by the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) to provide background information to inform and contribute to the drafting of *Health and social responses to drug problems: a European guide*.

The EMCDDA is grateful to the author for this valuable contribution. The paper has been cited within *Health and social responses to drug problems* and is also being made available online for those who would like further information on the topic. However, the views, interpretations and conclusions set out in this publication are those of the author and are not necessarily those of the EMCDDA or its partners, any EU Member State or any agency or institution of the European Union.

Introduction

This short paper outlines the growth of user-led interventions across Europe in the problem (as opposed to recreational) drug sector over recent years. It starts by attempting to define and categorise user-led interventions before describing a number of examples and sharing what is known about their effectiveness. The paper concludes by identifying likely developments, highlighting the opportunities created by user-led work and detailing the challenges for policymakers and commissioners in Europe.

It is important to note that this paper is not based on a comprehensive survey of user-led initiatives in Europe, nor does it seek to list the many organisations and programmes operating in this space. Indeed, it does not appear that a survey of user-led services has ever been carried out. Hunt et al. (2010) point out that there are several difficulties in surveying the user-led provision accurately, since some organisations have a short lifespan and stigma means that there are good reasons for certain organisations to avoid being too visible. In addition, the extent to which users or ex-users are involved in leading a specific organisation is not always clear.

Hunt et al. (2010) also trace the history of drug-user organisations in Europe to the Netherlands in the 1970s. Theo van Dam (2008) credits Nico Adriaans as the founder and chairman of the first advocacy/activist group, Rotterdam Junkie Union (RJB), in the Netherlands in 1977. Around this time, van Dam and Daan van der Gouwe also started Landelijk Steunpunt Druggebruikers (LSD) to try to get the Dutch Government to support users and user groups, reduce stigma and shape opinion around legalisation (Jezek, 2000). Initially, harm reduction was an offshoot of the drug users' movement, notably including Dutch activists who established the world's first needle exchange programme, set up by the MDHG Belangenvereniging Druggebruikers (Interest Association for Drug Users) in 1984 (Tops, 2006).

Definition

We have sought to use a simple working definition of user-led interventions, seeking to make the definition as transparent as possible so that readers can choose to agree or disagree, but are also clear about the meaning in this document.

Nevertheless, this has proved difficult to do for three principal reasons:

1. User-led organisations that grow and thrive often become a formal type of organisation with paid staff, albeit in very different, private, non-governmental organisation (NGO) or civil society forms.
2. Many initiatives are operated jointly by ex-/current users and non-using individuals.
3. There are differences between the users of different drugs. Montañés Sánchez and Oomen (2009) identified three types of organisations according to the profile of the users and the scene in which they use drugs: cannabis users, party drug users and users of street drugs such as opiates and cocaine.

As already stated, this paper focuses predominantly on this third category of problematic drug use.

We have decided to emphasise the fact that all the interventions discussed in this paper were at least predominantly initiated by current or former drug users and continue to be mainly directed by users. We distinguish this approach from service user involvement, in which treatment or other agencies lead an initiative or even peer support services, which are organised and/or supported and supervised by such agencies.

Our working definition of user-led interventions is:

Activities which are predominantly designed and delivered by current or former drug users.

Categories

We have chosen to examine user-led activities in five categories:

1. mutual aid (typically fellowships where current and ex-users support each other);
2. recovery enterprises (relatively large recovery-focused communities and networks that include any or all of supportive accommodation, recovery cafes and social activities, social enterprises and employment schemes, peer support, etc.);
3. harm reduction (where current or former users provide information and advice on how to use drugs safely);
4. advocacy (arguing for the rights or fair treatment of drug users);
5. research (conducting peer-research projects).

In each category below, we give examples of the range of projects across Europe, summarise any evaluations or other information about their effectiveness, and highlight the main opportunities and challenges for policymakers and professionals. It should be noted that we know more about user-led recovery and advocacy initiatives than other categories, so the five sections are necessarily of different lengths. It should also be noted that although user-led initiatives are increasingly common, evaluations are comparatively rare.

Mutual aid

By mutual aid, we typically mean fellowships where current and ex-users support each other.

The largest and best-known mutual aid organisation for drug users is Narcotics Anonymous (NA) ⁽¹⁾, a global, community-based organisation with a multilingual and multicultural membership. NA was founded in 1953, and its membership grew slowly during its first 20 years. However, since the publication of the Basic Text in 1983, the number of members and meetings has increased dramatically. Today, NA members hold nearly 67 000 meetings weekly in 139 countries, including all EU member states. NA promotes recovery from addiction through a 12-step programme, including regular attendance at group meetings. The group atmosphere provides help from peers and offers an ongoing support network for dependent users who wish to pursue and maintain a drug-free lifestyle. Membership is free, and NA has no affiliation with any organisations, including governments, religions, law-enforcement groups, or medical and psychiatric associations. The core service is completely provided by current or ex-drug users.

There are many more mutual aid organisations of different sizes. Different from the 12-step model of NA is the ‘science-based’ SMART recovery ⁽²⁾ model; originating in the United States in 1994, it has grown into a worldwide network of self-help meetings, both face to face and online, where participants can get help from others in recovery. SMART operates as a non-profit organisation in many countries including Denmark, Ireland, Spain, Sweden and the United Kingdom.

L’Isola di Arran ⁽³⁾ is a peer-support organisation founded in 1996 in Italy; its membership comprises both current and ex-drug users, and workers in the addictions field. The organisation has been involved in a wide range of activities (see later sections) and works with a number of national and European networks to promote the peer-support approach.

⁽¹⁾ <https://www.na.org/>

⁽²⁾ <http://www.smartrecovery.org/>

⁽³⁾ <https://isoladiarran.wordpress.com/chi-siamo/>

There are also a number of informal mutual aid organisations where members provide help and support in a large number of ways, including sourcing medication online to help home detoxification and providing general out-of-hours support for those struggling to remain abstinent.

Recovery enterprises

By recovery enterprises, we mean relatively large recovery-focused communities and networks that include any or all of supportive accommodation, recovery cafes and social activities, social enterprises and employment schemes, peer support, etc.

Europe has a number of well-known and long-established treatment communities run by former users; probably the two best known are San Patrignano in Italy and Synanon in Germany.

San Patrignano

San Patrignano, in Rimini, Italy, is described on its website as ‘a community for life that welcomes those suffering from drug addiction and marginalisation and helps them to once again find their way thanks to a rehabilitation programme that is above all, a programme based on love. It is free, because love is a gift.’ ⁽⁴⁾

The community is led by ex-users, and houses and interacts with almost 1 500 residents at any one time. Since its founding in 1978, it has served more than 18 000 people, at no charge. The resident group is diverse, and includes families with children. Some residents are human immunodeficiency virus (HIV) positive. The community provides medical care through a sizeable hospital within the site. Residents receive training to prepare them for possible employment in a range of trades and professions.

A follow-up evaluation (Castrignano, 2005) of 97 residents who spent three years or longer in the San Patrignano community found that 60 % had stopped taking drugs two to four years after leaving the community.

Synanon

Synanon is a therapeutic community for recovering drug users which was formed in 1971, and more than 25 000 former users have lived at the centre in the past 45 years. Although most residents are German, Synanon has also welcomed many people from the Czech Republic, Poland and Ukraine.

The centre is run by former users and this is reflected in the composition of its board. The city-based community currently has a capacity of 150 beds; there is normally no waiting list and clients are welcomed at any time of day.

After an initial detox stage, clients then begin to discuss future ambitions, prospects and responsibilities, and this is then reflected in how they spend their time with Synanon. Many residents stay with Synanon for two or three years, giving them the time not only to complete treatment but to start rebuilding their lives with a new profession (Synanon offers a wide range of education programmes, and training and employment in the transport, gardening, construction and catering sectors), new skills, increased confidence and a new group of non-drug using friends. The centre is financed through donations, government grants and profit from its work programmes.

An evaluation (Fredersdorf, 2000) found that many Synanon residents (between 33 % and 60 % of those who stayed at least two weeks) were abstinent from drugs and alcohol on follow-up, and more than two thirds were happy with their social networks, which comprised mainly people who were not active drug users.

⁽⁴⁾ <https://www.sanpatrignano.com/about-us/>

United Kingdom

There is currently a very strong movement in the United Kingdom for recovery to be supported and led by local communities, and in particular the local communities of recovering drug users and their families and friends.

Many organisations offer a wide range of support services, including, in particular, easy-to-access social support (e.g. London's Build on Belief (BOB)) ⁽⁵⁾, often provided in 'recovery centres (e.g. the Basement Project, West Yorkshire) ⁽⁶⁾, housing in drug-free accommodation with support from recovering peers living in the same house (e.g. The Well in several locations in the north-west of England) ⁽⁷⁾ and individual support from 'recovery coaches' (Emerging Futures in north and central England) ⁽⁸⁾.

These organisations have relatively small numbers of staff and rely on large numbers of volunteers, almost all of whom were or are problem drug users. Similarly, a very large majority of the paid staff are recovering drug users.

Several of these organisations pursue the asset-based community development (ABCD) approach to building recovery systems, which prioritises the local community's leadership and ownership of interventions. Emerging Futures espouses a 'mid-point allegiance' approach, described as 'working concurrently with social care treatment providers and the members of the communities they are commissioned to serve', which involves building the capacity of local communities to co-produce responses to problem drug use.

Most of the organisations seek to preserve a user-led ethos and governance structure, to ensure that they do not become too bureaucratic and professionalised as they grow and are formally commissioned by health and social services. One example of this is the way that Emerging Horizons, a private training and consultancy organisation set up by ex-users, launched Emerging Futures as an NGO (in a legal format known as a community interest company) in 'a conscious move towards operating according to core organisational values' ⁽⁹⁾. This legal status allows staff (most of whom are ex-users) and accredited recovery coaches (all of whom are ex-users) to call upon their mutual knowledge and experience of recovery to support individuals and communities directly.

Many of these organisations are recent and there are a limited number of independent formal evaluations. However, several of these organisations are looking to prove their value and assess their effectiveness. BOB has commissioned three separate evaluations, most recently a pair of aligned evaluations in 2014 into the impact of BOB on service users and on volunteers (mainly people in recovery), respectively. Both studies found positive outcomes in the domains of recovery from substance misuse, improved health and wellbeing, and reintegration into society.

In the United Kingdom, there has been a growing acknowledgement among those responsible for commissioning drug treatment and recovery services of the importance of commissioning service-led organisations to provide a recovery support system. The issues of ABCD and co-production are increasingly discussed, and there is an acknowledgement of the added value (and value for money) that these organisations can provide, particularly during a period in which public funds for social care services are reducing year on year.

In most areas, however, the amount of funding spent on user-/community-led recovery services remains a small proportion of the total treatment budget. There is an opportunity for commissioners to make limited

⁽⁵⁾ <http://buildonbelief.org.uk/>

⁽⁶⁾ <http://thebasementproject.org.uk/>

⁽⁷⁾ <http://www.thewellcommunities.co.uk/>

⁽⁸⁾ <http://www.emergingfutures.org.uk/>

⁽⁹⁾ <http://www.emergingfutures.org.uk/who-we-are/>

funding go much further and strengthen local recovery systems by increasing the proportion of funds distributed in this way. There are a number of related challenges:

- Commissioners need to be flexible in their procurement procedures to ensure that processes and procedures relevant to relatively large, formal organisations do not exclude user-led groups from funding (while, of course, ensuring that public money is still properly spent).
- User-led organisations need to adhere to their original principles as they grow, and to ensure that they continue to respond to the needs of new problem drug users, including those from different local communities, and those who use new drugs or established drugs in different ways.
- Commissioners need to recognise that it may be appropriate to measure the impact of these services not just on service users but also on the peers, volunteers and sessional staff who have themselves embarked on a recovery journey.

Harm reduction

By harm reduction, we mean groups of current or former users who provide information and advice on how to use drugs safely.

User-led harm-reduction work normally takes one of four forms:

1. providing information or training sessions to users on safer drug-use techniques or the administration of naloxone to prevent fatal opiate overdoses;
2. attending dance events or festivals to provide similar information, in addition to vitamins and fluids, and psychological support for those having 'psychedelic emergencies' or 'bad trips';
3. providing online information and advice about safer drug use;
4. analysing pills and tablets to inform potential consumers of their active ingredients.

The organisations involved in the final two categories (providing online information and analysing substances) typically comprise both active drug users and other interested parties (medical professionals, forensic scientists and researchers), and are not necessarily user-led. For more information about the work of this sort of body, please refer to the European Network for Rave Culture and Drug Awareness, known as BASICS ⁽¹⁰⁾, whose members run a number of peer projects across Europe.

Information/training

Since its establishment in 1989, German JES network (Junkies, Ehemalige, Substituierte — Junkies, Ex-users, Substitution clients) users have been involved in its harm reduction initiatives at various levels.

An interesting and effective collaboration has existed for the past 10 years between the 'AIDS Hilfe' NGO in Oldenburg and the local JES group, whose members provide safer use and safer sex education to prison inmates.

In some cities, such as Bonn, Braunschweig, Cologne, Osnabrück and Stuttgart, JES groups have become an integral part of the local network of drugs services, and carry out important tasks, such as needle and syringe exchange. The project 'JES-Seminars' is characterised by combining knowledge from self-help and acquired expertise. To promote the professionalism of activists in JES groups, the network conducts self-organised training sessions for users, to increase and expand the competencies of people who use drugs.

L'Isola di Arran (see mutual aid section) works in partnership with the informal Turin-based group Indifference Busters (whose membership consists of current and ex-drug users) ⁽¹¹⁾ on a range of harm-education initiatives, including mixed training for peers, peer operators and professionals aiming to spread information and knowledge on hepatitis C virus (HCV) (alongside an oral testing service), in addition to outreach work distributing sterile injecting equipment.

IN-Mouraria ⁽¹²⁾ is a harm-reduction centre in Lisbon, Portugal, which was created by people living with HIV and HCV, some of whom were active drug users. The centre provides social and health services, including peer support. Peers provide information, escort clients to services, perform rapid testing (HIV/HCV/hepatitis B virus, syphilis) and also deliver a comprehensive advocacy service. Although IN-Mouraria is now a formal organisation, it honours its service-user-led origins; decisions about the project are taken by the whole team, which comprises both paid workers and peer workers (many of whom are former users of the project).

⁽¹⁰⁾ <https://drugscouts.de/de/page/basics>

⁽¹¹⁾ <https://liberobreaker.wordpress.com/>

⁽¹²⁾ http://www.gatportugal.org/projetos/inmouraria-pessoas-que-usam-drogas_1

The Scottish Drug Forum (SDF) has run a peer naloxone training programme since 2012 ⁽¹³⁾, and a European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) systematic review (2015) identified 21 studies of take-home naloxone initiatives underpinned by educational and training interventions, although only six of these were European (five in the United Kingdom, and one in the United Kingdom and Germany). The review concluded that one study found evidence of a decrease in overdose-related mortality and weaker evidence that this form of peer intervention improves knowledge and forms positive attitudes towards the correct use of naloxone. We acknowledge that in the case of the SDF, this harm-reduction initiative is led by professionals although, clearly, the naloxone interventions themselves are delivered by users.

Festival/event work

A Hungarian organisation, DAATH ⁽¹⁴⁾, comprising people who use drugs and who call themselves ‘a psychedelic community’, attend trance parties and festivals to provide a range of information, advice and support services.

DAATH publishes the events and festivals that it will be attending in advance so that interested individuals can make contact with them easily.

The fact that the information is provided by drug users for drug users means that there is little questioning of its accuracy.

There are a number of other user-led organisations that carry out this kind of festival work, including Kosmicare ⁽¹⁵⁾, at Boom festival in Portugal, and Kosmicaid, in the United Kingdom ⁽¹⁶⁾.

Although this type of intervention does not focus on the street drugs typically associated with problematic use (opiates, cocaine, amphetamine), the user-led approaches essentially address an important need that would otherwise mainly be left unmet.

Online information

DAATH

DAATH also provides an online database of ecstasy tablets giving information about active

Tripsit is a drug-related harm reduction network that was formed on Reddit in 2011, for the purpose of aiding people under the influence of drugs who were having a difficult time ⁽¹⁷⁾. It is an international collective of people, many of whom are current users of psychedelic drugs, whose mission is ‘to provide open discussion of harm reduction techniques and positive support’. The Tripsit network comprises an internet relay chat team that offers 24/7 live support — predominantly to people who are undergoing negative experiences of drug use in real time — and a drug-information wiki and live radio service. Tripsit is particularly well known for its drug combinations chart (available in a range of European languages), which highlights high-risk combinations of substances.

⁽¹³⁾ <http://www.sdf.org.uk/drug-related-deaths/naloxone-peer-educator-initiative/>

⁽¹⁴⁾ <http://www.daath.hu/>

⁽¹⁵⁾ <https://www.boomfestival.org/boom2016/boomguide/kosmicare/>

⁽¹⁶⁾ <https://kosmicaid.org/>

⁽¹⁷⁾ <https://tripsit.me/>

Analysing pills

Energy Control was founded in Barcelona in 1997 and pioneered work reducing the risks associated with recreational drug use⁽¹⁸⁾. The organisation comprises both active drug users and non-users who have concerns about recreational drug use; it provides a range of harm-reduction activities including information, advice and training, and an international drug-checking service.

Effectiveness

Montañés Sánchez and Oomen (2009) claimed that user-led organisations have had a positive impact on harm-reduction work:

‘Many of the programmes that are currently carried out by official state programmes (like drug testing, syringe exchange, opiate prescription, user rooms, etc.), form part of claims that have surged from these organisations themselves, and in some cases, these programmes are being elaborated by drug user organisations, which have become more professional by converting themselves into service providers.’

The authors also argued that this professionalisation has helped to reduce the stigma attached to many drug users, by demonstrating that users can represent themselves effectively.

Advocacy

By advocacy, we mean user-led groups established to argue for and promote the rights or fair treatment of drug users.

An EMCDDA paper (EMCDDA, 2013) identified, via a survey, 218 drug policy-advocacy organisations in Europe, and found that 16 % (35) of these were involved in self- or peer-advocacy work, although only 5 % (11) of the organisations were classified as being user groups (some organisations were run by the families of drug users or were community activist groups focused on specific places or issues).

The report found that peer-advocacy organisations were involved mainly in awareness-raising activities (92 %), lobbying (44 %), and education and training (44 %). Peer advocates were more likely to use activist tools than were professional or public-policy advocacy groups. For example, Act Up-Paris⁽¹⁹⁾, an organisation for people living with HIV/acquired immune deficiency syndrome (AIDS), tries to garner support for drug-consumption rooms, harm reduction and the legalisation of cannabis by using public demonstrations and campaigns.

The largest proportion of peer organisations advocated for harm-reduction services (44 %), although sizeable proportions were concerned with prevention, abstinence and drug-free recovery services (25 %), and with the liberalisation of controls on drug use (22 %).

EuroNPUD

The world’s largest and best-known drug-user-led advocacy organisation is the International Network of People who Use Drugs (INPUD)⁽²⁰⁾, whose mission is to promote the health and defend the rights of people who use drugs. INPUD states that it will expose and challenge stigma, discrimination and the criminalisation of people who use drugs, and their impact on the drug-using community’s health and rights. It further states that it will achieve this through processes of empowerment and advocacy at the international level, while also supporting empowerment and advocacy at community, national and regional levels.

⁽¹⁸⁾ <http://energycontrol.org/international.html>

⁽¹⁹⁾ <http://www.actupparis.org/>

⁽²⁰⁾ <http://www.inpud.net/>

There is also a European Network of People who Use Drugs (EuroNPUD) in the early stages of development. An initial project sponsored by the EMCDDA in 2011 developed a directory of 30 separate user organisations described in the project's final report (Albers, 2011), although four entries representing national networks were composed of anything from 4 to 50 local groups. All of the groups described themselves in a project questionnaire as being for people who use heroin and other opiates, for injecting drug users and for people receiving prescribed opiates as part of a substitution programme.

The main activities of these groups were:

- syringe patrol and distribution (64.3 %);
- advice on safe drug use/harm reduction (85.7 %);
- help with treatment (64.3 %)
- help with housing (35.7 %);
- help with training (71.4 %);
- nursing (21.4 %);
- wound care and basic healthcare (57.1 %);
- food (42.9 %);
- legal aid (50.0 %).

In 2015, ViiV healthcare provided EuroNPUD with financial support to strengthen and develop its volunteer-based network. The organisation's mission statement is 'To protect the health and promote the rights of people who use drugs' ⁽²¹⁾.

This allowed EuroNPUD to appoint a coordinator and develop a management structure, with a steering committee of country representatives that decides the strategy of the network. The broad-based steering committee also provides a pool of advocates who are being trained to operate at a high level, both intervening at the European Union (EU) level and lobbying for change in national governments.

EuroNPUD is in the process of applying for membership of the EU Civil Society Forum for Drugs and is also seeking regular engagement in the EU HIV Civil Society Forum. EuroNPUD has successfully engaged with the Drugs Civil Society Group, which is a mechanism for liaison and partnership work between 20 regional and global drugs civil society networks, and with the United Nations Office of Drugs and Crime (UNODC) Global HIV/AIDS Programme.

Drug-user unions

A number of countries have drug-user unions. Four examples are included below.

The Swedish Drug Users Union (SDUU) was formed in 2002 by a group of users in Swedish opioid substitution programmes. Membership now comprises 'users of all legal and illicit drugs as well as users who have or wants substitution treatment' ⁽²²⁾. The SDUU mission statement cites the organisation's belief in human rights, equal treatment and zero discrimination of and towards all drug users. Its work primarily includes advocacy work for individual drug users and lobbying on policy (particularly harm-reduction) issues. It also makes an annual award to an individual or organisation for being user-friendly ('Brukarvänspriset').

The Danish Drug Users Union (Brugerforeningen (BF)) was formed in 1994 and represents active drug users ⁽²³⁾. The organisation, which receives funding from national and local government, sits on various Copenhagen City Council committees that consider policy and practice around illicit drug use and marginalised

⁽²¹⁾ <https://www.euronpud.net/what-we-do/>

⁽²²⁾ <http://www.svenskabrukarforeningen.se/>

⁽²³⁾ <http://brugerforeningen.dk/>

populations. It also contributes, by invitation, to national government debates and discussions. The BF also operates a syringe patrol which involves members safely disposing of discarded injecting equipment.

Autosupport des usagers de drogues (ASUD) is the first French drug-user union ⁽²⁴⁾, established in 1993 during the AIDS epidemic among intravenous drug users, and recognised by the authorities to represent drug-users' interests at many levels, including access to health, citizenship and political reform. ASUD's main goals are to promote drug-policy reform, the development and scale-up of harm reduction, and peer support.

Consumidores Associados Sobrevivem Organizados (CASO) was the first association of drug users to be established in Portugal ⁽²⁵⁾; its main goal is to promote the rights, health and dignity of drug users, which it does by developing education strategies for drug users, communicating harm-reduction messages, and working in partnership with treatment providers, commissioners, and local and central government.

Research

By research, we mean peer-led investigations into the lives and treatment experiences of drug users.

Peer research is becoming more and more common in the drugs sector, although it remains typically led and organised by academic or other 'professional' researchers who train and support peer researchers for two main reasons:

1. to reach current drug users for up-to-date information on current treatment provision or drug markets;
2. to help drug users in recovery to develop new skills and to earn legal income.

Local drug-user involvement groups are often commissioned to undertake 'mystery shopper' exercises to audit the quality of local service provision.

However, there are examples of larger scale projects. User Voice ⁽²⁶⁾, a user-led organisation comprising ex-offenders and/or drug users, was commissioned by the UK Government (via its National Health Service) to undertake research into the use of new psychoactive substances in prisons in England and Wales. The report ⁽²⁷⁾, published in 2016, was credited as the main impetus for government departments to respond to what was seen as an emerging crisis threatening the health and safety of prisoners and prison staff.

A leading UK organisation in the field of peer research with people experiencing multiple disadvantages is the Revolving Doors Agency ⁽²⁸⁾, which runs an 'experts by experience' team ⁽²⁹⁾, and has published a guide to the approach (Terry and Cardwell, 2016). A recent example of their work is a study of prisoners' experiences of opioid substitute treatment (Webster, 2017).

Discussion

As part of this paper, the author spoke with a number of individuals who had been involved in the founding, development and leadership of these organisations. They identified three key challenges:

1. It is only through the continued involvement of government departments and agencies of user-led organisations that an effective dialogue can be created which ensures that treatment and harm-

⁽²⁴⁾ <http://www.asud.org/>

⁽²⁵⁾ <http://casoportugal.wix.com/wwwwwwcomcasoportugal>

⁽²⁶⁾ <http://www.uservoice.org/>

⁽²⁷⁾ <https://drive.google.com/file/d/0BzKDGOPNokMDVmVhYIVxN2VnS3c/view>

⁽²⁸⁾ <http://www.revolving-doors.org.uk/>

⁽²⁹⁾ <http://www.revolving-doors.org.uk/involvement>

reduction services meet the needs of drug users. It can take several years for state- and user-led groups to understand each other's viewpoints, concepts and vocabulary.

2. User-led groups require funding to develop and become representative of a large number of drug users with different views, and they must be formally and explicitly allowed and encouraged to criticise treatment provision. While some user-led groups eschew official funding to guarantee both the reality and perception of their independence (turning in some cases to new forms of fundraising such as crowdfunding, for example through sponsored events) ⁽³⁰⁾, others argue that official funding for representative user groups should be direct and easy to access.
3. The most substantial barrier to the development of a more accessible and effective treatment system in most European countries is the range of negative, stigmatising and stereotyping attitudes to drug use and drug users. The representation of user-led groups in official forums, working parties, etc., means that the media is more likely to engage with these groups, and a more informed and balanced discussion of drug users and their needs can emerge (as has happened in Sweden over the past five years as a result of the work of the SDUU), with an eventual positive influence on national treatment networks.

Conclusion

There are two main conclusions to emerge from this paper. Firstly, it is clear that there is continued growth in the number and impact of user-led organisations in many different countries across Europe. Secondly, however, it is often difficult to distinguish between user-led organisations, NGOs and other types of organisation that were often founded by service users but which now comprise mainly paid staff, albeit with ex-/recovered drug users constituting a substantial proportion of the workforce.

Those interviewed in the course of preparing this paper suggested three major differences between those organisations that continue to be user-led and those that have transformed into more formal bodies, typically delivering services contracted by national or local government departments:

1. User-led organisations are often less constrained in terms of the campaigning and advocacy work they perform, particularly in pushing for changes in the legal system governing drug use.
2. User-led groups are often more adept at ensuring that the needs of harder-to-reach drug users (particularly those not using harm-reduction or treatment services) are identified and addressed, and at engaging more effectively with the broader community (both using and non-using) in a local area.
3. User-led organisations are more likely to offer support to their members/users on a 24/7 basis, although we do not have evidence to suggest how long such organisations can sustain these levels of comprehensive support. While organisations such as NA have survived, thrived and expanded for generations, there are many, mainly unrecorded, examples of other such user-led organisations which have not prospered after their founders' withdrawal.

Perhaps the most important, if tentative, conclusion of this paper is that many user-led organisations naturally develop into more formalised services which, in many cases, is essential in providing a more reliable and secure funding base.

This process can make a valuable contribution to reducing the stigma attached to many problematic drug users by governments and wider society. However, this 'professionalisation' also presents a key challenge for these organisations to retain their ethos and culture of being user-led, and to ensure that their governance, direction and key activities continue to be based on the wishes of the users they serve.

⁽³⁰⁾ For example <https://www.justgiving.com/crowdfunding/philip-platts-2>

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